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LIFE-PROLONGATING AND LIFE-TERMINATING TREATMENT OF SEVERELY HANDICAPPED NEWBORN BABIES.

A discussion of the report of the Royal Dutch Society of Medicine on "Life-terminating actions with incompetent patients; part I: severely handicapped newborns".

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1.THE KNMG-REPORT

Introduction

In 1988 the KNMG (Royal Dutch Medical Association) published a discussion paper written by a special commitee about life-terminating actions with incompetent patients, part 1: severely handicapped newborn babies [1]. All those involved in medicine, medical ethics and medical law were invited to submit their in reactions. In 1990 [2] a more definite report was published in which the committee had integrated the reactions received as far as they meant an improvement. This report is the first of a number of papers dealing with incompetent patients; publications about comatose patients and other categories of incompetent patients will follow. The ethical acceptability of terminating medical treatment and life-terminating actions with severely handicapped newborns is the central issue in the first report.

The aim of this article is to give a short summary of the KNMG-report, based on the report's own summary, and discuss the position it defends.

Summary of the KNMG-report

In the report the term life-terminating actions is defined as: "all acts of physicians aiming at the death of an incompetent patient, irrespective of the question whether it concerns the application of euthanatics, pain-treatment, not beginning or ceasing a treatment or anything in between". Because in the Netherlands the definition of euthanasia implicates the free request of the patient, this word is not used for life-terminating actions with incompetent patients.

In the present practice of neonatal intensive care, life-terminating actions almost exclusively consists of the ceasing of initially started life-supporting treatment or measures.

(The discussion paper of 1988 mentions 10 cases of actively terminating the life of a newborn (i.c. 0-3 months) by the application of euthanatics, of about 300 cases of life-terminating actions in the broader sense just mentioned. In the final report these numbers are not mentioned).

Decisions about the termination of a life are generally decisions made by a team of physicians; the influence of parents and nurses is relatively small. The main reason for terminating the life of a severely handicapped newborn baby appears to be the prognosis that the baby almost certainly is not viable or almost certainly will have an "unlivable life". However, the criteria for this differ from one hospital to another and from one physician to another, both with respect to medical and non-medical criteria (psychological factors and ethical considerations of the physician, situation of the parents etc.)

The report defends the moral stand for life-terminating actions, both when it concerns the forgoing of certain treatments and the active killing of a baby. The latter is considered acceptable only in situations when life-prolonging measures are terminated in anticipation of the death of the baby, but against expectation, the baby doesn't die. In such cases it can be morally defensible to administer euthanatics, according to the report.

In the performance of life-terminating actions, certain "requirements for careful medical practice" should be met. In all cases there should be certainty, according to general medical practice, about the diagnosis underlying the prognosis. As long as this certainty is lacking, the committee considers it permissible to keep the patient alive by artificial means, in spite of the medical ethical rule 'in dubio abstine' (in case of doubt refrain from treatment) - provided the treating physician is willing to forgo life-supporting measures and possibly terminate the patient's life if the final prognosis appears to be infaust. This prognosis should not just be based on personal experience and intuition but it should also correspond with the statistics available.

With respect to the prognosis: no real chance to survive, more consensus within the profession is desirable. The 'unlivable life' prognosis should be defined more precisely, because of its more subjective character. In this regard the profession should develop a generally accepted frame of

reference that will enable the determination of the character, seriousness and extent of the newborn's defects (to be expected). The definition of the limits: of what should or should not be called an unlivable life, is not merely a task of the profession, according the committee. Society at large should participate in this.

The application of such general criteria should, in individual cases, always leave the necessary liberty to do justice to those concerned, especially the parents.

For a responsible decision about life-terminating actions, a careful decision-making procedure is also considered necessary. Especially the opinion of the parents should be an important element in weighing the interests. Also nurses should be more involved in the decision-making.

Particularly if the parents and the attending physician do not agree, consultation of an experienced and independent colleague by this physician is considered indispensable. The responsibility remains with the attending physician. Also in view of good terminal care the life-terminating action should be performed by the physician and should be done "lege artis". Therefore, according to the committee, the information about the necessary prescriptions should improve.

A last requirement for careful medical practice is for the attending physician to write a correct account of the facts and considerations leading to the final decision.

With respect to the concept: 'medical useless treatment' the committee notes a clear distinction in interpretation between physicians and lawyers. According to physicians, also the 'unlivable life' prognosis can make life-supporting treatment medically senseless, whereas according to lawyers only strictly medical factors may play a role in the judgment whether a treatment is medically useless or not.

According to the committee it is necessary to solve this difference in opinion as soon as possible, since it hinders the possibility of control of life-terminating actions.

A second difficulty in controlling this, is constituted by the lack of guarantee for the physician who terminates the life of a patient according to the requirements, that he will not be prosecuted. As long as the government does not provide such a guarantee, the committee considers it unreal to expect that physicians will correctly record the cause of death in the case of the termination of a patient's life.

The committee considers it desirable to take life-terminating actions out of the sphere of criminal law and instead have an internal evaluation before such an action is performed with the possibility of control by a medical disciplinary court after the action.

2. COMMENTARY

The main problem.

This reaction to the KNMG-report will concentrate on a central moral problem in the report. The question is whether there is a moral difference between, on the one hand, not starting or terminating a treatment and letting the patient die, or on the other hand, the active termination of the life of a patient by means of 'euthanatics'. In both cases it concerns seriously and incurably ill people.

Life-terminating actions

The KNMG-report gives the following definition of life-terminating actions: "all acts of physicians aiming at the death of an incompetent patient irrespective of the question whether it concerns the application of euthanatics, pain-treatment, not beginning or terminating a treatment, or anything in between". This definition of life-terminating actions in itself already implicates some very important choices. Not intervening and letting die is bracketed together with active killing if both actions aim at the death of the patient. So, when the report speaks of ceasing or not initiating a treatment as a life-terminating action, apparently it has to be presumed this is done with the intention for the patient to die. Furthermore, it is stated (though this is in the annex that deals with the criticism to the first version of the report) that the moral quality of an action is not determined primarily by form, but by intention. This must lead to the conclusion, that letting die with the intention that the patient *will* die, and killing, should be considered morally equal. (The question whether in medicine the intention to kill can ethically be acceptable at all will be treated later). However, in the paragraph about the notification of death it is stated that the death of a patient "caused by terminating or not beginning a treatment because this is considered medically useless, pertains to the concept of natural death". At the same time, the report asserts "that in the case of life-terminating acting by means of the administration of euthanatics, no statement of natural death can be delivered". In other words, the committee is of the opinion to let die and to kill should juridically continue to be judged differently, also if in both cases the intention is the same, namely to bring about the death of the patient. So, according to the report in the medical ethical evaluation, one should consider primarily the intention, the form being of secondary importance, whereas in the juridical evaluation the form is considered to be of prime importance. One certainly should distinguish between an ethical and a juridical evaluation. But in the report, the ethical evaluation is so exclusively related to the intention, and the juridical to the form, that these two ways of evaluation are separated from each other in an untenable way.

Non-treatment as cause of death.

In my opinion, the definitions and distinctions given in the report obscure rather than clarify the medical ethical problem. This especially applies for the contentions that the aim of ceasing or not beginning a treatment is, or at least can be, the death of the patient, and that in those cases ceasing or not beginning the treatment is the cause of death of the patient. These two assertions are closely related in the report. Because death is seen as the *result* of not treating (any longer), one can *aim at* death with non-treatment. Reversely: when the non-treatment cannot be seen as the cause of death, it cannot aim at death either. It is incorrect to assert that non-treatment or ceasing treatment on the one hand and the application of euthanatics on the other, have the same causal relation to the death of the patient. The moral equality of these two activities can be maintained only when the actions of a physician and the final result for the patient are abstracted from the total medical situation. For this abstraction suggests a causal relation between the (non)activity of the physician and the death of the patient. The difference between 'doing' and 'letting' becomes clear when the total situation of the patient, the motives of the physician and the patient and the means that are used or not used, are taken into consideration. If this is done, to presume that treatments are (always) stopped or not started with the intention to terminate life is clearly incorrect. Of course in doing so the physician *can* have the intention to terminate the patient's life, but this certainly is not necessarily so. Therefore, without further information, terminating treatment cannot be seen as the direct cause of death. It is much more plausible to say the patient died because of his illness that appeared to be incurable. To end treatment (not care, which in my view involves the provision of food and fluids, cf. further) in these situations can be justified medically-ethically if the treatments themselves add suffering without offering real improvement. On the other hand, the administration of euthanatics is, by definition, an action that aims at the death of the patient. It is, in fact, a direct act of killing another person.

Cause and duty

The observations made in the previous paragraph may give rise to the question whether there is never a certain causal relationship between non-treatment and the death of a patient. This certainly can be the case. W.C.M. Klijn, a Dutch moral theologian, has correctly pointed out, that the question whether non-treatment must be seen as (a) cause of the death of a patient, depends on the question whether the treatment of the illness that without intervention will lead to the death of the patient, must be considered good medical practice; i.e., is it part of the physician's duty to care (zorgplicht)? [3]. In other words: Was it possible for the physician to treat the patient and thus prevent death in a

medically and ethically responsible way? The problem therefore is: what is a medically and ethically responsible way?, in other words: what does the physician's duty to care involve? (The word care is used here in a broad sense, including both curative and palliative treatment). When should the physician abstain from further treatment, acknowledging that medicine cannot help the patient any further? Which care, which support and help of the suffering and possibly dying patient continues to be required? This, it seems, is the correct way of phrasing the problem. It is noteworthy the KNMG-report uses similar words in formulating the problem under study. However, as demonstrated above, the discussion of the issue is obscured by the incorrect definition of life-terminating actions and the way this influences the reasoning in the report, leading to ethically objectionable conclusions.

Incorrect distinction

The KNMG is right in drawing the attention to the problem as just formulated. The report rightly rejects predomination of medical practice by what can be done technically. However, I do not agree with the solution the committee presents. It mentions two kinds of prognosis that can prompt a physician to abstain from further treatment. These are the 'no-real chance to survive' prognosis and the 'unlivable life' prognosis. In the first case the newborn baby has "with a probability next to certainty, no chance to survive". It is clear that in such cases no treatments to prolong life should be started, but only treatments to alleviate suffering in dying. The unlivable life prognosis concerns "defects that are compatible with life, but not with a life that is considered loveable". Here the report opens the door to a subjective evaluation of the livability of the life of a patient. This will give rise to arbitrariness with respect to the protection a handicapped baby will receive. This is even clearer from the criteria put forward to determine whether somebody's life should be considered livable. These are:

-The expected measure of suffering (not only bodily but also in the sense of (not) having perspective, hope),

-The expected possibility to:

. communication, to establish relations,

. independency (being able to move, to self-care, to live independently),

. self-realization (being able to hear, see, read, write, labor),

-The life-expectancy.

In this context the report speaks about marginal values, without making these concrete, that those criteria should reach in the life of a patient, in order to make his life livable.

3.ANOTHER APPROACH

In my opinion this whole approach is incorrect. The distinction between the 'no real chance to survive' prognosis and the 'unlivable life' prognosis should not be made at all. Instead the distinction between the useful versus useless medical treatment should be given a more prominent place. The KNMG-committee also uses this distinction, but the contents of the words 'useful' and 'useless' are determined by the 'unlivable life' concept. When according to the physician, for a certain patient the unlivable life prognosis applies, consequently any medical treatment aiming at prolongation or improvement of life is considered useless. However, the prognosis should not so much refer to the so-called livability of life, since this is a non-medical value judgement, but should consider the effect of the eventual medical treatment.

Useful and useless medical treatment.

The clarification of the concepts 'useful medical treatment' and 'useless medical treatment' is not only helpful for a reflection on the problems in neonatology, but also for medicine in general. It will be attempted to elucidate these concepts in discussing an article of a Dutch philosopher of medicine, F.C.L.M. Jacobs, about 'medically useless treatment' and 'useless medical treatment' [4]. Jacobs asserts that between these two terms a distinction should be made. Medically useless treatment is treatment that based on mere medical criteria, according to standard medical practice is useless; i.e. such treatment will not bring about an improvement of the biological-physiological functions. This judgement typically falls under the competency of the physician. On the other hand, useless medical treatment is treatment that based of objective medical criteria could or would have positive effects, but from which the physician abstains (should abstain) because it does not fit in with the subjective wishes or interests of the patient or because the life that would be prolonged by such treatment has no perspective any longer. In the judgement 'useless medical treatment' a value judgement about the quality of life is implicit. However, this is not a purely medical opinion and therefore it does not fall primarily under the competency of the physician but under that of the patient himself, or his solicitor. The biological-physiological level of human existence serves of the higher levels, which provide the criteria to determine whether medical treatment is useless or useful. For Jacobs, life and with it the continuation and maintenance of the bodily existence, is useful when the person is or will be able to experience his or her life as useful. Biological life only merits respect as a basis for biographical life, according to Jacobs.

Applied to the issue under discussion, these insights of Jacobs, if well understood, imply that a decision not to start or to stop treatments on the basis of the unlivable life prognosis is not a purely medical judgement. Therefore, according to Jacobs it does not fall primarily under the competency of the physician but, in the case of newborns, of the parents. Jacobs's approach seems to be similar to that of the report, but he limits the competency of the physician and clarifies the considerations that underlying the decisions to stop treatment and eventually even terminate life. In itself this can be considered as gain. But in my opinion Jacobs does not offer a philosophically and ethically acceptable solution. Before presenting my view on the distinction between useful and useless medical treatment, the different views of man that ly behind the different positions with respect to the ethical limits of medical treatment will be dealt with .

Dualistic view of man

Both the KNMG-report and Jacobs implicitly start from a dualistic concept of man as this originated in the course of the history of our culture. (Generally Descartes is seen as the 'father' of this concept [5,6]). This dualism on the one hand gave origin to modern medicine which is based on natural sciences. On the other hand modern medicine in turn has furthered and maintained this dualism in our culture. This can be formulated in different ways. Jacobs, for example speaks about the body-object on one hand and about the subject which can lead a biographical life on the other. Here the concept of the body is materialistic and mechanistic. The subject, the 'I' is characterized by self-consciousness, the ability to communicate and by other capacities necessary to experience life as meaningful. True humanity, which makes life of man meaningful, resides in the subject. The functioning (and existence?) of it is completely dependent on the body-object. If the body is damaged to such an extent that the subject can not manifest itself any longer in an useful way or does not even exist any longer, the physical existence has become useless and can be terminated. This view of man has been called characteristic for ethical approaches in which the 'quality of life' concept is central [7]. A fundamental problem in this context is that the body-subject division is not just devised in the course of our history, but this dualism has become very much the real experience of western man [8]. Nevertheless, it misses the full meaning of human life. Medicine taking this dualism as it's starting point and using a quality of life ethics related to it, implies a threat for many persons in our society.

Man as a unity

The human being, in my view, is characterized by a duality of body and spirit. Neither can the body

be reduced to the spirit, nor the spirit to the body. The spirit surpasses the physical existence, but must not be seen as independent from it. That which qualifies the human being resides neither just in the spiritual nor in the physical aspect, nor is it related specifically to one particular organ or one particular function, but it is given with the human being as such. The wholeness of the human being as it manifests itself in life, should have priority over the diversity in aspects and dimensions that can be distinguished in it. The different dimensions, functions and organs of man receive their meaning from the whole, being at the same time a unity. The body should not be understood as a vehicle of the subject nor of the spirit. The body is not a thing that 'I' have but is body ('Leib' in German), manifestation, medium of expression of the spirit, animated form of the human being. In his corporeity the creatureliness of man and the relation to God, to other human beings and to the world come together [9]. Therefore the human body ultimately is not biologically qualified but religiously [10].

In a Christian view of life, the question whether life is useful or not is not determined by functions or capacities that can be objectivized to a certain extent. The value and the dignity of man reside in being created by God and in the calling to live in relationship of love with God, one's fellowmen and creation. In these relations the physical existence is fully involved. At the same time, especially the relationship to God withdraws from observation from outside.

This view implicates that also the life of severely physically and/or mentally handicapped patients, or comatose patients, or patients with a severe psychiatric illness or with dementia, deserve full protection. Their lives are not a mere biological existence robbed of its meaning, because there are no longer any personal relations or there no longer is conscious biographic life. (This is not necessarily Jacobs's opinion; his criterion "being able to experience life as meaningful" is not completely clear. It does suggest however, that some of the groups of patients just mentioned do not fulfill this criterion).

In practice one can take a position similar to that just presented without sharing the Christian outlook on life, e.g. from a humanist approach stressing the equal right to life and to medical treatment of every human being, independent of his capacities or condition.

Control

Does this view of man imply that one always has to continue treatment and even prolong a process of dying? Certainly not. The Christian view of life acknowledges and accepts the finiteness and the mortality of the physical existence is (though death is not considered good in itself). Postponement of death or the prolongation of the dying process *in itself* is certainly not the highest good of medical

ethics. Life is given; as such man can neither dispose of his own life, nor of the life of somebody else, but he is responsible for it. So there is an a priori responsibility for man to maintain and protect his own life as well as that of others. Medicine has to be seen in this context. Therefore, medical actions which maintain life and actions consciously terminating life, in principle are not at the same level. These two kinds of interventions do not intervene in life in morally equal ways [11].

Granted, when the life of a patient is consciously terminated, death is not aimed at because of death itself, but to do away with the suffering. But when the life of a patient is consciously and directly terminated to stop the suffering, the patient is identified with his suffering to such an extent that the person who is always there in the suffering, disappears completely [12]. Principally, I think this is wrong. Medicine should fight suffering because of the person and should not turn against the person because of his suffering.

In extreme situations it is understandable that the patient, for the experience of those involved, almost completely coincides with his suffering. Even then, a conceptual identification is incorrect and neither from a medical nor from an ethical point of view can it be maintained that the intention of terminating treatments necessarily is the death of the patient (see above). But this obviously is the intention when euthanatics are administered. So, in this case there is a complete identification of the person with his suffering.

A factor behind this seems to be an aspiration for control [13]. Aiming at the death of a patient implies the identification of the patient with his suffering and/or his condition to such an extent that in order to remove the suffering or to stop the 'inhuman' condition, the patient's life is terminated. The endeavor to control life's conditions leads to disposing of life itself. This requires a specific decision of the will and a 'mental turn' in the attitude to the patient [12]. It is not without reason that almost all physicians have great reservations against the direct application of euthanatics, especially for the first time.

The moral equalization of 'killing' and 'letting die' also seems to be connected to an aspiration for control over life. Its justification 'requires' the disproportionate and sometimes incorrect concept of causality that is found in the KNMG-report. Only when the life and condition of the patient would be completely controlled by medical technology, can its withdrawal be considered as the cause of death [14]. It should be acknowledged that modern medicine, because of its dualism with its mechanistic medical concept of the body, and because of an excessive confidence in medicine and medical technology, easily gets the character of an instrument to control life. However, such a complete dominion is in fact impossible, if only because (biological) life is ultimately an uncontrollable

phenomenon. But it is also undesirable. When medicine is practiced as an instrument to control life, the patient is treated according to the abstractions of the medical model and this always implies a form of violence [15]. So, although sometimes medicine temporarily needs to (try to) control the condition of the patient, it should not try to master life itself. Medicine should always be practiced in an attitude of assistance, of service to the life of the patient.

Manifestations of an undesired striving for control can be seen both in aiming at the death of a patient in certain cases and in continuing treatments till the 'bitter' end, without a good balance between often uncertain profits against certain burdens.
The KNMG-report rightly warns against dominion in the form of 'medical fanaticism', but the report does not take distance from control in the form of aiming at the death of a patient (be it by 'doing' or by 'terminating'), just the contrary. The standpoint of the report in this respect is, in my view, connected with the dualistic view of man and a corresponding quality of life ethics.

Terminating medical treatment.
Now I come back to a problem mentioned above, namely a further clarification of the terms 'useless medical treatment' and 'useful medical treatment'.
First, the words 'medical treatment' in the expression 'useless medical treatment', or as Jacobs describes it 'medically useless treatment', should not be limited to actions intending to affect biological-physiological functions of the patient. Such a description is the expression of an incorrect view of man as described above. A physician always treats a human being as a totality. Even if he or she thinks the concrete actions occur mainly or even exclusively at the level of the body. Medicine must *serve* human beings; this means it should try to (help) protect their lives, (help) cure illnesses and alleviate suffering.
Secondly, a distinction should be made between those actions and interventions that essentially belong to the care which always should be offered to every patient, and those interventions and equipment used, aiming at curing or replacing a normal function of the body. To the former treatments belong bed rest, personal hygiene, food and fluid [16], and treatments that prevent or alleviate pain. The latter include medication, surgical interventions, dialysis, respirators, transfusions, transplantations and so on. Medically useless are those treatments (of the latter category) performed on incurable people, with the aim to maintain or prolong life, whereby the possible therapeutic effect does not counterbalance the suffering caused by the treatment itself and its side effects. In other words: medically useless treatments are disproportionate treatments. When

in a certain situation treatment is terminated and equipment is withdrawn, this is not done with the intention to bring about the death of the patient because his (physical) life would be meaningless. The physical existence should not be seen as merely instrumental. The human being is indeed meant to live in personal relationships. When a health problem hampers or frustrates the realization of this design, it is the task of medicine to try to bring about recovery or improvement. When, according to medical standards, the realization of this design of human life has become completely and definitely impossible at the level of human relationships, treatments started to bring about or facilitate improvement (not treatment that maintains the patient's condition), can be stopped. Not because the life of such a patient would have become meaningless - the most fundamental relation, that with God, withdraws from our observation - but because medicine should not dominate life, but serve it and acknowledge the limitations of its possibilities and the finiteness of life. Treatments are not terminated on the basis of an evaluation concerning the meaning of life of the person, but on the basis of an evaluation of the meaning of that treatment for the life of that person. The latter evaluation in fact can contain an element of the former. However, it seems to us that in the 'borderline situations' in which this is the case, it is inherent to the practice of medicine. A physician should not become an engineer of the human body, materialistically conceived, but should maintain the attitude of subservience to the patient, which in the first place implicates full respect for his life, but not an absolutization of life-prolongation.

However, if curative treatment is stopped, the earlier mentioned basic care should continue. In some cases, pain-treatment can imply a shortening of life. For example, when one has to conclude that the prolongation of artificial respiration does not serve any medically-ethically justified goal and that ceasing would subdue the patient to a process of several hours of dying by suffocation. Even in such a case it should be stated conceptually, that the shortening of life is not brought about to cause death, but to shorten and alleviate an already started and unavoidable dying process full of suffering [17]. In such extreme situations such a way of proceeding can be considered the lesser of two evils. In itself such a treatment cannot be called a moral good. Therefore, those cases should not be taken as a starting point for regulations of legislation. These situations draw our attention in a poignant way to the brokenness of our existence for which the people involved directly do not bear specific personal responsibility, but which can be understood as a common existential guilt of mankind [18].

In conclusion

Obviously, this discussion of the issue put forward and discussed in the KNMG-report does not provide an answer to many of the concrete questions asked in this context. For example, the

question: who decides? has not been dealt with [19]. However, I do hope it contributes to the reflection on a difficult and central problem of modern medicine in a way that is helpful, also for those who do not share my basic beliefs.

Notes

1.KNMG-committee "Acceptability life-terminating actions". Life-terminating actions with incompetent patients. Part 1: Severely defected newborns. A discussion paper. Medisch Contact 1988; 43, nr. 22: 697-704 (in Dutch).

2.KNMG-committee "Acceptability life-terminating actions". Life-terminating actions with incompetent patients. Part 1: Severely defected newborns. An interimreport. Medisch Contact 1990; 45, nr. 17:553-563 (in Dutch).

3.Klijn WCM. Hoge Raad. Wetenschap en levensbeëindiging. Medisch Contact 1989; 44:919-22.

4.Jacobs FCLM. Medisch zinloos handelen en zinloos medisch handelen. Medisch Contact 1990; 45:541-4.

5.Ten Have H. Medicine and the cartesian image of man. Theoretical Medicine 1987; 8:235-46.

6.Foss L. The challenge to biomedicine: A foundation perspective. J Med Philosophy 1989; 14:165-91.

7.Reich WT. Article: Quality of Life, Encyclopedia of bioethics. New York: Free Press, 1978:829-40.

This is not to say that only a dualistic concept of man can lead to a justification of euthanasia, biological monism also can. However, at present the dualism seems to be the predominant concept behind the defence of euthanasia.

8.Cf. for example: Levin DM, Solomon GF. The discursive formation of the body in the history of medicine. J Med Philosophy 1990; 15:533.

9.For an extensive description and defense of this position, cf. Eibach U. Medizin und Menschenwürde. 3rd Ed. Wuppertal: Brockhaus, 1988:56-66, 82-86.

10.In the Christian tradition this is demonstrated e.g. by the saying in the creed: "I believe the resurrection of the body" and by the objections that traditional Christianity and Judaism have against cremation.

11.Cf. Blokhuis P. Hulpverlening als kwaliteitsbeheersing? (Care as quality control?). Medisch Contact 1989; 44:745-8.

12.Eibach U. Medizin und Menschenwürde, 3rd Ed. Wuppertal: Brockhaus, 1988, esp. 247-363.

13.Cf. Oderwald A. Ideologie van de dood? (Ideology of death?) In: Rolies J.(red.). De gezonde burger. Nijmegen: SUN 1988: 125-39. This is not to say that physicians consciously experience this aspiration for control as such; it rather concerns the role that medicine and health care get in our society.

14.Callahan D. Can we return death to disease? Hastings Center Report 1989; 19, no. 1. Special supplement, p. 4-6.

15.Porto EAM. Social context and historical emergence: the underlying dimension of medical ethics. Theoretical Medicine 1990; 11:145-165.

16.I realize there is a discussion, both in the USA and in Europe about the question whether the artificial administration of food and fluid should be considered as medical treatment, to which the same rule of proportionality applies as to all curative treatment, or whether in principle it should be considered as an element of basic (palliative) care that should be provied until the patient dies. I take the latter position, recognizing the artificial application of food and fluids **can become** a disproportionate treatment because of the burden and suffering it imposes on the patient in itself. An extensive discussion of this problem is beyond the scope of this article. I only refer to some literature in which is argued roughly as I would do.

Rosner F. Withdrawing fluids and nutrition: An alternate view. New York State J. Med., Nov. 1987: 591-592.

Smith WB. Is a decision to forgo tube feeding for another decision to kill? Issues in Law and Med. 1991; 6, no. 4:385-394.

17.I have the impression my position sounds rather similar to the "best interests of the child" position, defended, among others,by:

Arras JD. Ethical principles for the care of imperiled newborns. Toward an ..... of ambiguity. In: Murray TH, Caplan AL. Which babies shall live? Clifton (New Jersey): Humana Press: 1985:83-135, and by

Greenstein LJ. Withholding life-sustaining treatment from severely defective newborns: Who should decide? Med. Law 1987; 6:487-97.

I agree with the central idea of the "best interests" position, but it is obvious the concept of what are the best interests of a severely handicapped child depends on one's view of man. The two authors just mentioned do not state this explicitly, but it seems the position of both is rather similar to that of the KNMG-report under discussion, though Arras is more reserved and careful in his formulations.

18.Cf. Thielicke H. Wie mag sterven? (Who may die?). Ede: Zomer & Keuning BV, 1980: 36-40.

19.For a discussion of this question see, e.g. Greenstein LJ, see note 17.

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